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Public attitudes and knowledge of dementia: Northern Ireland, Republic of Ireland and Scotland

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Discussion paper
Public attitudes and knowledge of
dementia: Northern Ireland, Republic
of Ireland and Scotland

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August 2016

www.ark.ac.uk/ageing

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Introduction

Dementia has been recognised as a major health and social care issue across the world, especially given the changing demographic patterns associated with ageing populations. Measuring the public's understanding of dementia and associated risk factors can help inform public health campaigns. Attitudes are related to stigma, prejudice and discrimination, and so it is important to record these over time.

This discussion paper draws upon survey data from three countries in close proximity to each other: Northern Ireland, Republic of Ireland and Scotland. In 2014, many of the same questions on dementia were asked in at least two out of the three countries, thus providing us with important cross-national comparisons.

Prevalence of dementia

It is estimated that in 2015, there were 46.8 million people across the world living with dementia. Moreover, this number will almost double every 20 years, to 74.7 million in 2030 and 131.5 million in 2050 (Ali et al., 2015). In the same report, Guerchet and colleagues estimated that there will be a 9.9 million new cases of dementia in 2015, equivalent to one every 3.2 seconds.

This rise in the prevalence of dementia is a feature of the three countries covered in this report. In 2011, it was estimated that there were 19,000 people in Northern Ireland living with dementia, the vast majority of whom were aged 65 years or over (DHSSPS, 2011). However, this is expected to rise to 23,000 by 2017 and around 60,000 by 2051, due to population ageing (ibid.). Within the Republic of Ireland, the number of people living with dementia was estimated to be 47,849 in 2011, rising to 152,157 in 2046 (Department of Health, 2014). A similar pattern is expected in Scotland, with the number of people living with dementia estimated to double between 2011 and 2031 (The Scottish Government, 2013). Data for 2016 suggest that the number of people living with dementia in Scotland is 90,684 (Alzheimer Scotland, 2016),

Effective and timely diagnosis of dementia is important for the individual and their family. Whilst these figures above give an indication of the number of people living with dementia, not all of these people will receive an appropriate diagnosis, and diagnosis rates vary by region and country. For example, it is estimated that in 2012, around 64% of people with dementia in Scotland were being diagnosed, compared with 38% in Wales, 44% in England, and 63% in Northern Ireland (The Scottish Government, 2013). These rates can vary significantly at more local areas. In 2014, the figure for Northern Ireland overall was 64.8%, ranging from 55.9% within the Northern Ireland Health and Social Care Trust, and 72.9% within the Belfast Health and Social Care Trust (Alzheimer's Society, 2014). GPs in the Republic of Ireland are not have required to register the number of patients attending their surgery who have a diagnoses of dementia, thus making it difficult to estimate the diagnosis rate.

Dementia strategies

Whilst Northern Ireland, Republic of Ireland and Scotland are geographically close, they are legislatively disparate, as shown by the history of their respective dementia strategies. Scotland was the first of the three countries to publish a dementia strategy.

Scotland

The first *National Dementia Strategy* was published in 2010, and the second three-year Strategy (2013-2016) is now coming to an end. The third National Dementia Strategy for Scotland is currently being prepared.

The first strategy had a focus on improving the quality of dementia services through more timely diagnosis and on better care and treatment, especially within hospital settings. It also acknowledged the need to transform care across all sectors in anticipation of an increase in the number of people living with dementia. Since that first strategy, however, the need for timely and sensitive diagnosis, backed by effective and holistic post-diagnostic support, has been recognised. This is vital in helping build personal resilience and knowledge about dementia, and in enabling people with dementia live a good quality of life at home for as long as possible. Therefore, the second Strategy introduced a national commitment on post-diagnostic support for everyone diagnosed from 1 April 2013.

More information is available online at
<http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration/Dementia>

Northern Ireland

The *Improving Dementia Services in Northern Ireland - a regional strategy* was published in 2011. The main themes within the Action Plan of that document are to:

- reduce risk and delay onset of dementia;
- raise awareness;
- promote early assessment and diagnoses;
- support people with dementia and their families;
- support carers;
- develop legislation (such as the Mental Capacity Act, 2016);
- promote research.

The *Improving Dementia Services in Northern Ireland* strategy is available online at <https://www.health-ni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy>

Republic of Ireland

The first Irish National Dementia Strategy was published in 2014, and incorporates a set of principles underpinning the provision of care and supports for people with dementia. These include

- taking account of dementia in the development and implementation of existing and future health policies;
- encouraging the participation of people with dementia in society and in their own communities as fully as possible for as long as possible;
- prioritising end-of-life care in an appropriate setting for those with dementia;
- appropriate training and supervision for all those caring for or providing services to people with dementia;
- directing resources to provide the best possible outcome for those with dementia, and for their families and carers.

More information is available online at
<http://health.gov.ie/healthy-ireland/national-positive-ageing-strategy/the-irish-national-dementia-strategy/>

Dementia plans and strategies worldwide

Alzheimer's Disease International has produced a useful guide to Government Dementia Plans across the world – see <http://www.alz.co.uk/alzheimer-plans>

Attitudes about dementia

Whilst much of the research carried out in relation to dementia has focused on risks and protective factors, there has been less emphasis on exploring public attitudes (Reid, Waterton and Wild, 2015). Measuring attitudes is important, given the link between attitudes, stigma, prejudice and discrimination. By measuring attitudes over time, we can identify societal change, as well as linking these to changing government policies and practice. Thus, the use of public attitudes survey data can help inform public health messages and campaigns.

Public knowledge about dementia

As well as recording public attitudes about dementia, it is also important to assess public knowledge and understanding, in order to inform the level and content of public health messages and strategies. In particular, whilst many modifiable risk factors for developing dementia have already been identified, it is essential to record how much of that information is understood, and acted upon, by the general public.

Suzanne Cahill and colleagues undertook a systematic review of literature on the general public's knowledge of Alzheimer's disease, which was published in 2015. One of their main findings was that the general public only had fair to moderate knowledge and understanding about Alzheimer's Disease. The most common misconception was that dementia was a normal part of ageing. In addition, there was a lack of clarity about when normal age-related memory loss problems become severe enough to indicate dementia. This means that people may delay accessing appropriate diagnoses and support services.

Background to the surveys

This report provides a comparison of findings from three national surveys carried out in 2014/5: Scottish Social Attitudes, Northern Ireland Life and Times Survey, and Healthy Ireland (listed in order of date of fieldwork). Whilst the research teams from all three surveys were in contact with each other, and shared their questionnaires, not all questions were asked in all three surveys, for several reasons. In some cases, this was due to the specific policy focus of each survey. In the case of the Northern Ireland Life and Times Survey, the research team wanted to replicate some questions that had previously been asked in 2010, in order to see if and how attitudes had changed. This report focuses on questions that were included in at least two of the three surveys.

Northern Ireland Life and Times Survey

The Northern Ireland Life and Times (NILT) Survey is an annual public attitudes survey, carried out by ARK researchers based in Queen's University Belfast and Ulster University (see www.ark.ac.uk/nilt). This cross-sectional survey has been running since 1998, with the exception of 2011, and a random sample of approximately 1200 adults living across Northern Ireland take part each year. The data are weighted to take account of any biases that may arise due to people from larger households being under-represented in the sample.

Four key social policy topics are included each year, some of which are included annually, and others are repeated on a less regular basis. Funding comes from a variety of sources. In 2010 and 2014, the survey included a module of questions focusing on public attitudes to, and knowledge of, dementia. In both years, these questions were funded by the Atlantic Philanthropies. Findings from the 2010 survey are available from McManus and Devine (2011), Dowds et al. (2012), and McParland et al. (2012). Findings from the 2014 survey are available in Byrne McCullough and Devine (2015).

Scottish Social Attitudes

The Scottish Social Attitudes survey (SSA) is carried out by ScotCen Social Research, which is an independent research organisation based in Edinburgh. The 2014 survey involved 1,501 interviews with a probability sample of the Scottish population aged 18 years or over. Interviews were conducted face-to-face in people's home, with a self-completion element for questions that were particularly sensitive or where there were concerns about respondents giving 'socially desirable' answers. Data are weighted to adjust for known non-response bias and to ensure that they reflect the sex-age profile of the Scottish population.

In 2014, SSA included questions on dementia, which were commissioned by the Life Changes Trust and the Joseph Rowntree Foundation, as part of a programme of work to improve understanding and awareness of dementia, and to inform future policy in relation to developing a positive environment for people living with dementia. Findings are available in a report by Reid, Waterton and Wild (2015).

The Healthy Ireland Survey

The Healthy Ireland Survey was commissioned by the Department of Health. It is an interviewer-administered survey with interviews conducted on a face-to-face basis with people aged 15 or over. In 2014/5, the survey included a module of questions on dementia, which involved 7,539 interviews using a multi-stage probability sample. The data is weighted to overcome any biases that may arise due to individuals from larger households being under-represented in the sample, as well as non-response adjustments based on government population statistics. Findings from the survey are available in Ipsos MRBI (2015).

Comparison of survey findings

Whilst each of the three surveys included questions relating to dementia, some of these were unique to a specific survey. However, some questions were asked in at least two surveys, and the published data relating to those questions are compared in this section.

One issue to be aware of in these comparisons is the differing age groups participating in each survey. The surveys in Northern Ireland (NI) and Scotland were based on population samples aged 18 years or over, whilst the respondents to the survey in the Republic of Ireland (RoI) were aged 15 years or over. At the time of writing this discussion paper, a dataset with age in single years was not publicly available. This would have allowed the author to undertake analyses using the same age range across all three surveys. Another limitation to direct comparison relates to the purpose of the three surveys, which may affect how respondents think about the subject. NILT and SSA are public attitudes surveys, whilst the Healthy Ireland survey has a specific health remit.

Knowledge of dementia

At least half of survey respondents know someone with dementia, including a very small number of respondents who have dementia – see Table 1. In all three countries, the likelihood of knowing someone with dementia increased with age. The low minimum age of respondents within the Healthy Ireland survey may partly explain why the proportion of respondents knowing someone with dementia is lowest in Ireland.

Table 1: Knowing someone with dementia

	%		
	NI	RoI	Scot
No, I don't know anyone who has or had, dementia	35	47	24
YES	61	50	74
Yes, my partner or a member of my family	28	25	38
Yes, a friend(s) or acquaintance(s) I know less well	14	10	12
Yes, a friend(s) I know fairly well	12	7	17
Yes, my job involves / involved working with people who have dementia	8	3	16
Yes, a colleague / someone at my work	2	1	3
Yes, someone else	10	8	11
Yes, I have dementia myself	<0.5	<0.5	1
Not sure	4	3	2

In two of the surveys (NILT and Healthy Ireland), respondents were presented with four statements about dementia, and asked to indicate whether they thought whether each of them were true or false. The data suggest varying levels of knowledge about these four characteristics, and the same general pattern is visible for both surveys.

Table 2 shows that the majority of respondents in both surveys correctly identified that dementia is a disease of the brain. A smaller majority of respondents indicated that dementia is not a normal process of ageing. However, there was less understanding that dementia is not a mental illness, and less than one third knew that dementia is not another term for Alzheimer's Disease. In both surveys, there was greater understanding of these features of dementia by respondents who personally know someone with dementia.

Table 2: Knowledge of characteristics of dementia

	% correct	
	NI	RoI
Dementia is a disease of the brain (True)	87	85
Dementia is part of the normal process of ageing (False)	64	59
Dementia is a mental illness (False)	37	48
Dementia is another term for Alzheimer's disease (False)	24	33

Risk factors

Each of the three surveys explored public knowledge of risk factors for developing dementia. Respondents were presented with five statements relating to the role of heavy drinking, genetic factors, healthy diet, smoking, and high blood pressure in developing dementia. For four of the risk factors, the statement was true, whilst the statement relating to smoking was false.

However, the summary report for the Healthy Ireland survey (Ipsos MRBI, 2015) warns that whilst there is some indication that hereditary factors, and heavy drinking, are related to certain types of dementia, conclusive evidence has not yet been attained through empirical research.

In the Healthy Ireland survey, respondents were asked to indicate whether they thought each statement was 'true' or 'false'. However, within the Scottish and Northern Irish surveys, respondents were asked to indicate how much they agreed with each statement, using a five-point scale (strongly agree, agree, neither agree nor disagree, disagree and strongly disagree).

Table 3 shows the percentage of respondents who correctly identified awareness of each risk factor, and three general observations can be made. Firstly, overall awareness of these risk factors was low, with no factor being identified by more than 52 per cent of survey respondents. Secondly, those taking part in the SSA survey were most aware of the risk factors, and those taking part in NILT were least aware. Thirdly, a similar pattern of awareness was evident across all three surveys. For example, heavy drinking was recognised as a risk factor by the highest (Republic of Ireland and Scotland) or second highest (Northern Ireland) proportion of respondents, and high blood pressure was recognised least.

Table 3: Correct identification of risk factors for dementia

	% indicating 'correct response'		
	NI	RoI	Scotland
People who drink heavily are more likely to get dementia	32	44	52
If one of your parents gets dementia, you are more likely to get it too	33	42	39
If you eat a healthy diet you are less likely to get dementia	27	41	36
Smoking has nothing to do with dementia	23	35	37
High blood pressure increases your chances of getting dementia	19	20	22

A fourth observation is that there is a high proportion of respondents in NILT and Healthy Ireland survey who said that they did not know how to respond to these questions, especially in relation to high blood pressure (see Table 4). This suggests that public understanding and awareness of risk factors is limited, and much confusion exists. In general, the levels of respondents who gave a 'don't know' response in SSA is lower. Nevertheless, one in five SSA respondents gave that response in relation to high blood pressure.

Table 4: Respondents giving 'Don't know' responses to risk factors

	% saying 'don't know'		
	NI	RoI	Scotland
People who drink heavily are more likely to get dementia	24	27	8
If one of your parents gets dementia, you are more likely to get it too	21	24	9
If you eat a healthy diet you are less likely to get dementia	22	24	9
Smoking has nothing to do with dementia	27	33	11
High blood pressure increases your chances of getting dementia	36	44	22

Based on Reid, Waterton and Wild's report on the Scottish Social Attitudes survey, a 'composite score' for each respondent was calculated, giving each respondent a score of one for every 'correct answer'. Thus, the scale ranged from 0 (the respondent did not identify any of the risk factors) to 5 (meaning that the respondent correctly identified all five risk factors). Table 5 below shows the distribution of 'correct answers', as well as the average number of 'correct answers' given.

Table 5: Composite risk factor scores

Number of 'correct answers'	%		
	Northern Ireland	RoI	Scotland
0	38	23	21
1	24	24	24
2	16	22	23
3	10	18	17
4	7	11	12
5	3	4	3
Average composite risk factor score	1.34	1.82	1.86

These composite risk factor scores reinforce the earlier observation that knowledge of risk factors for dementia is particularly low in Northern Ireland. Thus, whilst around one in five respondents in Scotland and the Republic of Ireland were not able to identify any of the risk factors (21%), the figure for Northern Ireland was nearly twice that proportion (41%).

Caring for someone with dementia

Respondents to NILT or SSA were asked about their experience of caring or helping someone with dementia or who had symptoms of dementia, excluding any experience that they had as part of their job. As Table 6 shows, the pattern of responses was similar across both surveys. Around one in five respondents had helped someone from time-to-time, one in ten were caring for someone not living with them, and slightly lower proportions were caring on a regular basis for someone who does live with them. The main difference between the surveys related to visiting someone every now and then, which was undertaken by one in ten respondents in Scotland, but three times that proportion in Northern Ireland.

Table 6: Caring for someone with dementia

	%	
	NI	Scotland
Helped someone from time-to-time	20	20
Cared on a regular basis for someone who does not / did not live with me	11	12
Cared for someone (other than myself) who lives / lived with me	8	8
Been responsible for making arrangements for someone to be looked after (e.g. arranged for a carer to visit someone at home, or arranged for someone to go into a residential home)	8	5
Encouraged someone showing symptoms of dementia to seek professional help	9	2
Visited someone every now and then	29	10

Respondents to SSA and NILT were asked how much they agreed with three statements relating to caring for someone with dementia. Two of these acknowledge the negative effects of providing care on the carer. On the other hand, one of the statements acknowledges the rewarding aspect of caring.

Table 7 indicates that respondents had a strong sense that caring for someone can often be very lonely – four out of five respondents in both countries agreed with this statement. A slightly lower proportion (but at least 70%) agreed that caring for someone with dementia can result in detrimental health effects for the carer. At the same time, at least one half of respondents acknowledged the positive effect of caring with someone with dementia, and that this role can often be very rewarding.

Table 7: Caring for someone with dementia

	% agree or strongly agree	
	NI	Scotland
Caring for someone with dementia is often very lonely	79	83
Caring for someone with dementia is often very rewarding	54	57
Caring for someone with dementia often means your own health suffers	70	76

Dementia friendly communities

Alzheimer's Disease International describe a dementia friendly community as:

a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential.

(<https://www.alz.co.uk/dementia-friendly-communities/principles>)

They suggest that four essential elements are needed to support a dementia friendly community: people, communities, organisations and partnerships. Their website contains a useful directory of case studies of dementia friendly communities across the world, including examples in Northern Ireland, Republic of Ireland, and Scotland.

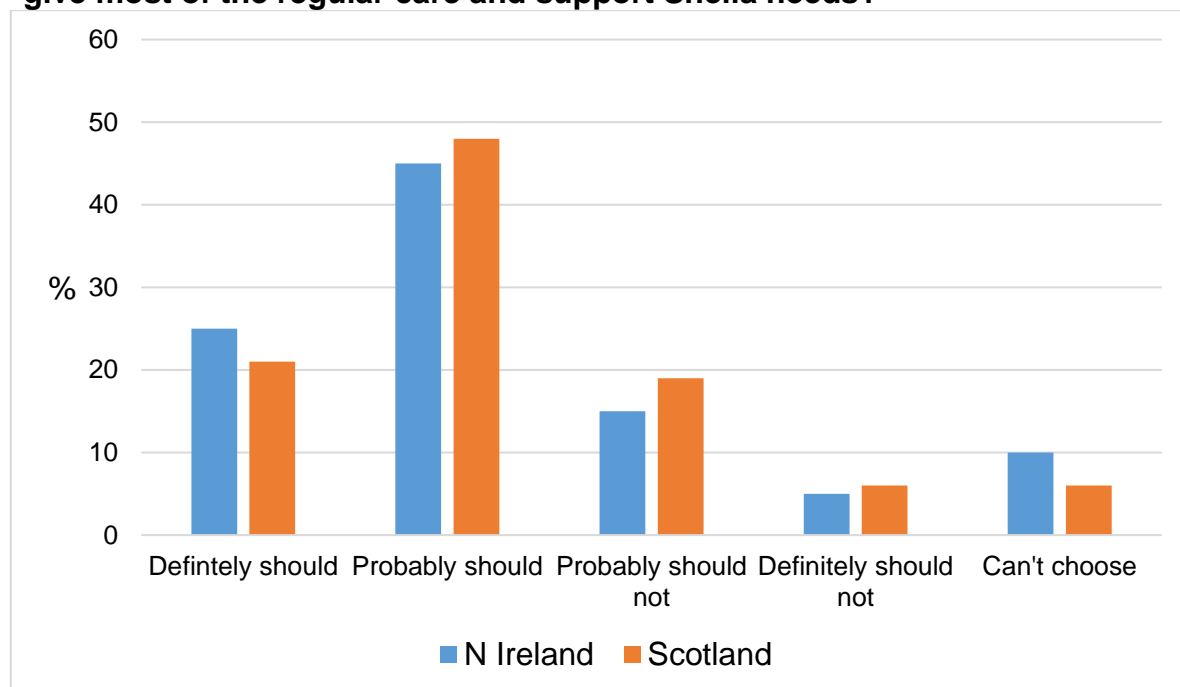
Two scenarios were included within SSA and NILT which tapped into the concept of dementia friendly communities. These questions focused on the expectation that family members will provide support, and willingness to help a neighbour. These questions were included in the self-completion section of the surveys rather than within the face-to-face questionnaire, in order to minimise 'social desirability bias'. Social desirability bias occurs when respondents answer questions in a particular way in order to cast themselves in a more positive light.

In the first scenario, respondents were presented with the following situation:

Sheila lives on her own. She has been retired from her job as a shop manager for 5 years. Sheila was recently diagnosed with dementia. She sometimes finds it difficult to do the shopping and cooking, and she can no longer manage her finances properly. Sheila has two children, who both live close by.

When asked whether Sheila's children should be expected to give most of the regular care and support that Sheila needs, a large majority of respondents in the two surveys (NILT and SSA) believed that they should (See Figure 1).

Figure 1: Do you think Sheila's children should, or should not, be expected to give most of the regular care and support Sheila needs?



Respondents were then asked about their own willingness to get involved with helping Sheila, whom they had known as a neighbour for several years. As Table 8 shows, whilst the vast majority of NILT and SSA respondents said that they would be very or fairly willing to do so, this was particular true of SSA respondents (89%, compared with 77% for NILT).

Table 8: Willingness to get involved with helping Sheila

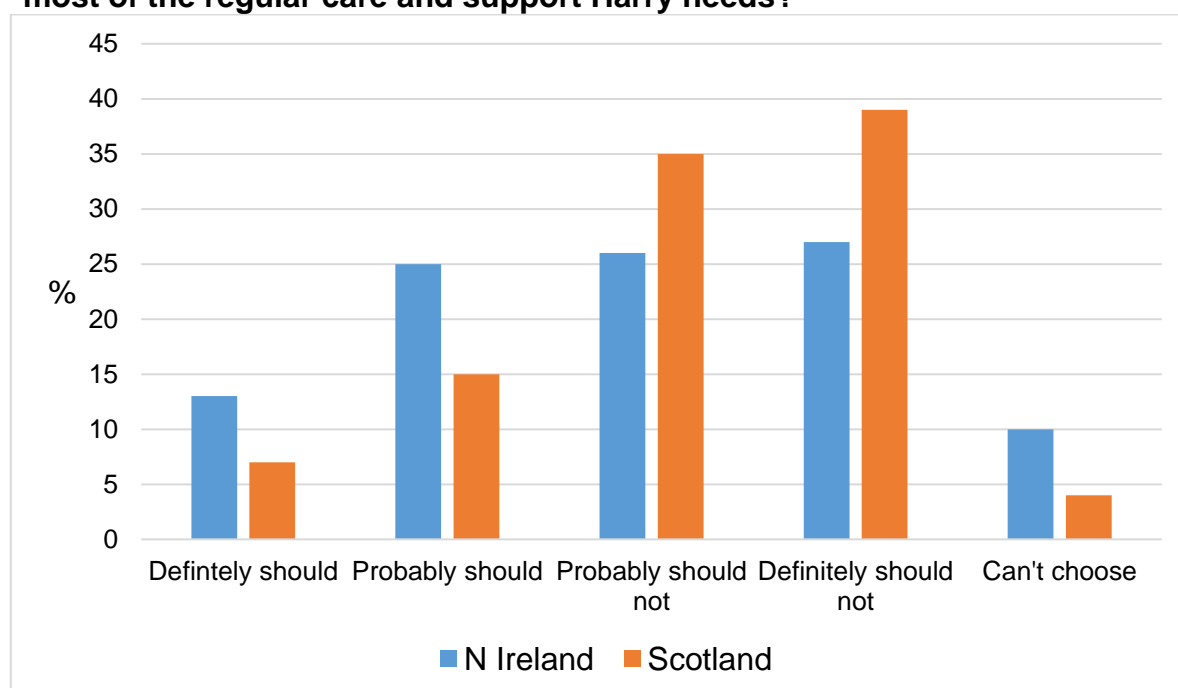
	%	
	Northern Ireland	Scotland
Very willing	28	31
Fairly willing	49	58
Fairly unwilling	9	7
Very unwilling	4	1
Can't choose/refused	10	4

The second scenario involved a more severe form of dementia, as well as a different family situation than the first:

Harry, aged 75, lives at home with his 72 year old wife Margaret, who is in good health. Harry was diagnosed with dementia 5 years ago. He isn't able to wash or dress himself and has quite unpredictable mood swings. Harry often doesn't know where he is or what day it is. Harry and Margaret have no children.

Whilst at least two thirds of NILT and SSA respondents thought that Sheila's daughters should give most of her care and support, this was not the case in relation to Harry and Margaret's situation (see Figure 2). In this scenario, the majority view was that Margaret should **not** be expected to give most of the regular care and support Harry needs. This could be for several reasons, including the more advanced stage of Harry's dementia, and Margaret's age. Another important feature of scenario 1 is the presence of Sheila's children, who were likely to be younger than Margaret, and, importantly, could share the caring role between them. In Figure 1, there was little difference between the two surveys. In contrast, Figure 2 indicates that SSA respondents were more likely than NILT respondents to say that Margaret should be expected to give most of Harry's care (74% and 53% respectively).

Figure 2: Do you think Margaret should, or should not, be expected to give most of the regular care and support Harry needs?



As in scenario 1, respondents were asked about their willingness to get involved with helping Harry and Margaret, who had been their neighbours for several years – see Table 9. As in the previous scenario, the majority of respondents indicated their willingness to get involved, with a higher proportion of SSA respondents than NILT respondents doing so (80% and 70% respectively). These figures are slightly lower than those show in Table 7, and perhaps reflect the advanced stage of Harry's dementia.

Table 8: Willingness to get involved with helping Harry and Margaret

	%	
	Northern Ireland	Scotland
Very willing	23	24
Fairly willing	47	56
Fairly unwilling	11	13
Very unwilling	8	3
Can't choose/refused	11	4

Discussion

This paper provides a snapshot of public knowledge and attitudes relating to dementia across three countries, using survey data from 2014: Northern Ireland, Republic of Ireland and Scotland. However, the impact of the different survey contexts and age groups puts some limitation on direct comparability of results.

The results presented here are mainly descriptive, and do not highlight where there are differences across groups (for example, according to age, caring responsibilities, knowing someone with dementia, income level etc). Such analysis is available for the three surveys separately: Byrne McCullough and Devine (2015) for Northern Ireland; Ipsos MRBI (2015) for Republic of Ireland; and Reid, Waterton and Wild (2015) for Scotland. Nevertheless, several key messages are evident.

Firstly, the majority of survey respondents know someone with dementia, and the likelihood of knowing someone with dementia increased with age. Thus, dementia is a condition that is pertinent in all three countries.

Secondly, knowledge of different facts about dementia is patchy. Whilst most respondents knew that dementia is a disease of the brain, less than half knew that it is not a mental illness. This finding suggests that a public health campaign that highlights facts about dementia would be useful.

Thirdly, overall awareness of risk factors for dementia is low, especially the link between high blood pressure and getting dementia. Again, this is a key public health message, and especially important in Northern Ireland given the low level of knowledge of these risk factors. A campaign that specifically focused on younger people could reduce the prevalence of dementia in the future.

Fourthly, the effects of caring for someone with dementia were acknowledged, both in relation to loneliness, and to health. At the same time, there was an acknowledgement that caring for someone with dementia is often very rewarding. The role of carers is vitally important, and so should be an integral part of dementia strategies (as in *Improving Dementia Services in Northern Ireland*).

Finally, acceptance of the level of support that families should be expected to give depends on the severity of the dementia and the age of the carer. This was also the case in relation to willingness of the respondent to get personally involved. The figures indicated that respondents in Scotland were more willing than those in Northern Ireland to get involved in helping a neighbour with dementia. However, despite being included on the self-completion questionnaires, social desirability bias must be taken into account.

Dementia strategies have been developed within all three countries. As these come to the end of their remit, empirical evidence about public understanding and attitudes is important for feeding into the development of the new documents. In addition, such information is pertinent for the formulation of public health policies and campaigns.

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ARK Ageing Programme

The ARK Ageing Programme is a resource within ARK to support engagement between the age and academic sectors. We do this by encouraging and facilitating the production of research that will support lobbying and advocacy, and the sophisticated use of information and evidence by the age sector. In addition, we aim to embed ageing research within Queen's University Belfast and Ulster University.

This programme of work will transfer existing knowledge between the academic, policy and voluntary and community sectors, as well as identify and fill key research and information gaps. These activities will be wide ranging, such as:

- recording public attitudes to ageing issues
- undertaking secondary analysis of key datasets
- holding research seminars and policy round tables on key issues identified by the age sector
- running research workshops for the voluntary and community sectors.

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For more information, visit www.ark.ac.uk/ageing or find us on Facebook.

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